

# **Expanding the Scope of Bioethics Mediation: New Opportunities to Protect the Autonomy of Terminally Ill Patients**

HAILEY AKAH<sup>\*</sup>

## **I. INTRODUCTION**

## **II. ETHICAL PRINCIPLES OF TERMINAL CARE**

- A. Modern Application of Ethical Principles*
- B. Cultural Differences in Applied Ethics*

## **III. PATIENT BURDENS AND CONFLICTING VALUES AT END-OF-LIFE**

- A. Patient Burdens*
  - 1. Social and Family Pressures on End-of-Life Patients*
  - 2. Procedural Pressures on End-of-Life Patients*
  - 3. Patients Struggle to Communicate with Health Care Payers*
- B. Failures in Training and Communicating with the Health Care Industry*
  - 1. Physician Training in End-of-life Issues*
  - 2. Grounds for Conflict Between Patients, Physicians, and Families*

## **IV. THE CURRENT ROLE OF BIOETHICS MEDIATORS**

- A. The Benefits of Bioethics Mediation*
- B. The Limited Scope of Bioethics Mediation*

## **V. BIOETHICS MEDIATION FOR COMPETENT PATIENTS AT END-OF-LIFE**

- A. Advocate for Patient Autonomy at End-of-Life*
  - 1. The STADA Process*
  - 2. Conflict Mediation*
- B. Address Cultural Concerns*
- C. Educate Patients and Practitioners*

---

<sup>\*</sup> Hailey Akah, Juris Doctor Candidate, The Ohio State University Moritz College of Law, 2016; B.A., Lawrence University, 2013. I would like to thank my fellow staff members at the *Ohio State Journal on Dispute Resolution* for their tireless editing work, my undergraduate and law school professors who have encouraged my academic pursuits, and my husband, Ebiji, who supports me in all things.

*D. Promote Increased Access to Palliative Care*

## VI. CONCLUSION

## I. INTRODUCTION

As American society becomes increasingly aged, and medical technology becomes increasingly advanced, when and how we die has become a complex, decision-laden process. Patients and their families must now decide what sort of treatment to receive, how invasive such treatment should be, when to consider hospice care, and ultimately, when to withdraw treatment. Cost, culture, and family dynamics inevitably shape this decisionmaking process. Families and physicians have opinions, there are financial realities to consider, and patients may find their cultural understanding of care at odds with the medical system. In the midst of these pressures and opinions, competent, terminal patients have preferences for their end-of-life care. Some will want to pursue every avenue for extending life. Others desire rest in their final days and will want fewer invasive procedures, if any. Although these preferences exist, they are often lost among the noise, or are never vocalized at all. For this reason, competent patients are often not able to control their own end-of-life process.

This note investigates the newly minted field of bioethics mediation and suggests that these mediators will be able to advance the desires of end-of-life patients. Part II articulates the bioethical principles that must be applied during bioethics mediation and addresses the difficulty of applying autonomy to its full extent. Part III outlines the burdens competent patients face at end-of-life, including pressures placed on them by their families, their hospitals, their insurance companies, and societal expectations at large. Part IV details the current, limited role of bioethics mediators, and Part V advocates for the expansion of that role. Although bioethics mediators are currently confined to mediations between health care providers and family members of *incompetent* patients, they are ideally suited for end-of-life patient advocacy. Bioethics mediators could be used to educate patients and families on end-of-life planning, promote increased access to palliative care, and advocate for patient autonomy over their treatment decisions. If used in these ways, bioethics mediators could assist competent, terminal patients in directing their own end-of-life care.

## EXPANDING THE SCOPE OF BIOETHICS MEDIATION

### II. ETHICAL PRINCIPLES OF TERMINAL CARE

Physicians owe four main duties to their patients: (1) autonomy, (2) beneficence, (3) non-maleficence, and (4) justice.<sup>1</sup> The obligations of non-maleficence, to avoid causing harm, and justice, to distribute benefits and risks fairly, are uncontested and apply fully in the end-of-life context.<sup>2</sup> Autonomy and beneficence are equally important; however, they stand in tension with one another. As a result, the intersection of autonomy and beneficence is critical to end-of-life care. Stated simply, autonomy is the physician's obligation to "respect the decision making capacities of the patient."<sup>3</sup> However, patient autonomy is more than having a choice between health care options. True autonomy exists when the patient can meaningfully shape the course of his or her health care in a way that holistically reflects the patient's "values, preferences, and beliefs within the context of her current, and evolving, life circumstances."<sup>4</sup> Beneficence, on the other hand, is the physician's obligation to provide benefits to the patient and to balance those benefits against the associated risks.<sup>5</sup> Beneficence requires the physician to use his or her medical expertise to bestow appropriate care upon the patient. There is an "uneasy détente" between autonomy and beneficence.<sup>6</sup> Beneficence requires physicians to provide care that is in the best interest of

---

<sup>1</sup> T. L. Beauchamp, *Methods and Principles in Biomedical Ethics*, 29 J. MED. ETHICS 269 (2003). Tom Beauchamp and his frequent co-author, James F. Childress, have been writing about these four bioethical principles since the 1970s. See, e.g., TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 32 (1st ed. 1979). Their approach to bioethics is based on these objective, universal principles, and through their writing, they assert that autonomy, beneficence, non-maleficence, and justice should govern not only moral behavior, but social policy and legislation as well. This approach has since become the "dominant paradigm" in bioethics. John D. Arras, *Principles and Particularity: The Roles of Cases in Bioethics*, 69 IND. L.J. 983, 986 (1994). Although the "principlist" method of bioethics is nearly ubiquitous, some argue that it is limited. For instance, some argue that a universal ethical code is an important descriptive framework for approaching bioethical issues, but is much less useful when solving novel ethical problems. See Alexander E. Limantani, *The Role of Ethical Principles in Health Care and the Implications for Ethical Codes*, 25 J. MED. & ETHICS 394 (1999). For the purposes of this note, the four basic principles of bioethics are understood as a necessary and useful foundation for approaching bioethics consultation and mediation.

<sup>2</sup> Beauchamp, *supra* note 1, at 269.

<sup>3</sup> *Id.*

<sup>4</sup> Barbara A. Noah, *In Denial: The Role of Law in Preparing for Death*, 21 ELDER L.J. 1, 14 (2013).

<sup>5</sup> Beauchamp, *supra* note 1, at 269.

<sup>6</sup> Noah, *supra* note 4, at 13.

the patient.<sup>7</sup> However, physicians must also allow patients to autonomously direct their own care. These principles cannot be applied equally because there is a natural tension between being cared for and making decisions. Both objectives can be accomplished, but in any given health care setting, either autonomy or beneficence will be emphasized over the other.

### A. Modern Application of Ethical Principles

In recent decades, there has been a switch in the ethical model of health care from beneficence to autonomy. In previous generations, the physician-patient relationship was defined by beneficence.<sup>8</sup> The medical community emphasized the expertise of physicians and their role as providers of care. Because of this, physicians were relied upon to use their knowledge, judgment, and skill in the best interest of the patient.<sup>9</sup> In contrast, medical culture today emphasizes patient autonomy. Instead of passively receiving benevolent care from an expert physician, patients rely on their doctors to provide them with all the necessary information so that patients can make their own informed decisions about their medical care.<sup>10</sup>

Despite its prominence, there are some difficulties with applying the autonomy model in the hospital setting. First, hospital care is both extraordinarily complex.<sup>11</sup> Health care teams are made up of many individuals, and medical decisions are often made in hectic situations with less than complete information. It is difficult to inform the patient and allow him or her to make treatment decisions when action must be immediately taken. It is similarly difficult when there is little information to give to the patient, and health care professionals must rely on experience and instinct. Second, the beneficence model has left lingering expectations in the minds of patients; patients sometimes assume that the physician's opinion is more important than their own.<sup>12</sup> Patients may not express their opinion out of respect for the physician or may neglect to form an opinion in deference to the medical team's expertise. Whatever the reason, autonomy does not appear as the dominant principle if the patient relies on the beneficence of the physician.

---

<sup>7</sup> *Id.*

<sup>8</sup> Mark Garwin, *The Duty to Care—The Right to Refuse Changing Roles of Patients and Physicians in End-of-Life Decision-Making*, 19 J. LEGAL MED. 99, 99 (1998).

<sup>9</sup> BARRY R. FURROW ET AL., *BIOETHICS: HEALTH CARE LAW AND ETHICS* 208–10 (3d ed. 1997).

<sup>10</sup> *Id.*

<sup>11</sup> Garwin, *supra* note 8, at 100.

<sup>12</sup> *Id.*

## EXPANDING THE SCOPE OF BIOETHICS MEDIATION

Although pure autonomy can be difficult to achieve, it is the preeminent value in modern American culture. Federal law, agency regulations, and hospital policy all impose a duty on physicians to allow their patients to make decisions autonomously.<sup>13</sup> In order to comply with this duty, physicians facilitate decisionmaking by providing patients with complete and accurate information about their illness and prognosis.<sup>14</sup> This is particularly important in the context of end-of-life care. When patients are facing severe physical and emotional pain, personal quality of life questions become especially pertinent.<sup>15</sup> In these instances, autonomy should be enhanced so that the compassion of the medical team, not their expertise, is in the forefront.<sup>16</sup> It is crucial that patients are able to direct their health care, indeed their very existence, at the end of their lives. Emphasizing autonomy over beneficence in these instances is critical to prioritizing compassion for the individual over medical custom.

### *B. Cultural Differences in Applied Ethics*

One crucial consideration for ethical health care, particularly at end-of-life, is the cultural perspective each individual brings to the process. First, it is important to recognize the values that mainstream American culture imposes on illness and dying. Second, health systems must recognize the ways in which other cultures differ from the American perspective.

American culture is highly individual, dynamic, and technologically-bound. As previously stated, patient autonomy is valued as an important right.<sup>17</sup> Many Americans believe that individuals should have control over their own end-of-life care. This means that patients should be well-informed by their medical team, and any information that could be important in the patient's decisionmaking process should be provided to him or her.<sup>18</sup> In this cultural mandate lies an ingrained preference for autonomy over beneficence. Well-informed patients who are given the ability to make competent decisions are preferred over ignorant patients who entrust themselves to knowledgeable medical professionals. Americans typically want every opportunity to shape

---

<sup>13</sup> Catherine Berglund, *Ethics: A Process of Reflection*, 22 MED. & L. 635, 641–42 (2003).

<sup>14</sup> *Id.*

<sup>15</sup> George P. Smith, II, *Gently into the Good Night: Toward A Compassionate Response to End-Stage Illness*, 22 TEMP. POL. & CIV. RTS. L. REV. 475, 477 (2013).

<sup>16</sup> *Id.*

<sup>17</sup> Pat K. Chew, *A Case of Conflict of Cultures: End-of-Life Decision Making Among Asian Americans*, 13 CARDOZO J. CONFLICT RESOL. 379, 383 (2012).

<sup>18</sup> *Id.*

their own life outcomes,<sup>19</sup> and that is seen particularly strongly at the end of that individual's life. In this vein, clear and effective communication between the patient and his or her medical team is crucial.<sup>20</sup> The individualistic and self-directed American cultural majority prefers to receive clear information about illness and prognosis and to have the opportunity to voice preferences clearly and directly.

Although these principles represent the majority of American culture, not every patient seen in the United States will have these values. For instance, Asian cultural norms and imperatives differ dramatically from those common to Western culture.<sup>21</sup> For this reason, it is useful to compare the Asian-American end-of-life perspective to the cultural majority in the United States. First, autonomy of the individual is not valued nearly as highly in Asian culture. For Asian-Americans, it is not the individual, but the family, who is the primary decisionmaker.<sup>22</sup> The family should then receive the pertinent information about the patient's illness and prognosis, and the patient should largely be kept uninformed.<sup>23</sup> This is out of love and protection for the patient, who is thought to fair better if he or she is not distraught over the illness.<sup>24</sup> Therefore, the clear disclosure that Americans desire from their health care professionals may be considered harmful by Asian-Americans. Additionally, many Asian-Americans do not speak as bluntly about death and dying. These topics are seen as sensitive or taboo, and discussing them openly is impolite.<sup>25</sup> This compounds with cultural differences in communication. Communication patterns in Asian-American culture are much more subtle and contextual than mainstream American communications.<sup>26</sup> Japanese culture in

---

<sup>19</sup> See, e.g., Walter A. Wright, *Practical Steps for Acquiring Cross-Cultural Negotiation Skills*, 70 TEX. B.J. 590, 591 (2007).

<sup>20</sup> Chew, *supra* note 17, at 383.

<sup>21</sup> *Id.* at 389–90. Acculturation, nationality, and age affect these statistics. See *id.* at 380–82.

<sup>22</sup> Marjorie Kagawa-Singer & Leslie J. Blackhall, *Negotiating Cross-Cultural Issues at the End of Life*, 286 J. AM. MED. ASS'N 2993, 2994 (2001).

<sup>23</sup> Chew, *supra* note 17, at 386. One study of Japanese-Americans revealed some differences by level of acculturation. Japanese-Americans who spoke primarily Japanese differed from Japanese-Americans who spoke primarily English. *Id.* at 386–87. The groups varied primarily on the role of the patient and the physician. *Id.* at 387. “The Japanese-speaking Japanese Americans were more deferential to the physician; the English-speaking Japanese Americans thought the patient could participate in the decision making.” *Id.* However, both groups of Japanese-Americans preferred the family to be the primary decisionmaker. *Id.*

<sup>24</sup> *Id.* at 389.

<sup>25</sup> Yu Xu, *Death and Dying in the Chinese Culture: Implications for Health Care Practice*, 19 HOME HEALTH CARE MGMT. & PRAC. 412, 412 (2007).

<sup>26</sup> Chew, *supra* note 17, at 388.

## EXPANDING THE SCOPE OF BIOETHICS MEDIATION

particular relies on “implicit communication” about end-of-life care with extensive use of nonverbal cues, such as “silence, pauses between words, eye-contact, affective posture, and nuance and tone in communication about unrelated topics.”<sup>27</sup> Advanced planning is therefore difficult to achieve, and questions and concerns of the family may be overlooked due to conflicting forms of communication. It is imperative for American physicians to keep these cultural differences in mind. If not, cultural conflict over treatment at end-of-life will continue.

### III. PATIENT BURDENS AND CONFLICTING VALUES AT END-OF-LIFE

#### A. Patient Burdens

Despite the cultural and ethical emphasis on autonomy, competent patients often have little control over their end-of-life care. The patient’s ability to express his or her preferences for the future is limited by familial expectations, procedural hurdles, and financial realities.

##### 1. Social and Family Pressures on End-of-Life Patients

First, familial expectations can weigh heavily on terminal patients. Family members often demand that every measure be taken to ensure extended life for their loved one. This can include highly invasive, painful, and expensive procedures. The patient may not want to spend their last years going through these types of treatments but may do so in order to appease caring and concerned family members. These familial expectations often originate from a “technological imperative” that exists in mainstream American culture.<sup>28</sup> The technological imperative insists that every life-extending treatment be tried in order to “beat” illness. Families, and society at large, often admire patients who “fight” to stay well and “do everything” to defeat illness.<sup>29</sup> The pressure to always try the next, best, or newest treatment option limits the patient’s ability to express his or her true values or preferences for care.<sup>30</sup> The

---

<sup>27</sup> *Id.* at 384.

<sup>28</sup> See M. Janet Barger-Lux & Robert P. Heaney, *For Better and Worse: The Technological Imperative in Health Care*, 22 SOC. SCI. & MED. 1313, 1313–20 (1986) (discussing how the increased prevalence of health technology has led to increased satisfaction among patients).

<sup>29</sup> Noah, *supra* note 4, at 1.

<sup>30</sup> *Id.* See generally, Lois Shepherd & Mark A. Hall, *Patient-Centered Health Law and Ethics*, 45 WAKE FOREST L. REV. 1427 (2010).

technological imperative may even mean that families never openly acknowledge the fact that the patient is dying.<sup>31</sup> Futility is another aspect of this multi-faceted problem. What counts as “futile” is subjective, and the patient, his or her family members, and the health care providers may disagree about the appropriate time to discontinue technological treatment.<sup>32</sup> The patient is therefore confined to one treatment path, and the autonomy of that individual is diminished.

Alternatively, the autonomy of patients may be limited by family circumstances. The patient may express the desire to be cared for at home, but family members may feel overwhelmed by the idea of taking care of a terminally ill loved one. The family members may fear they do not have the skills to adequately care for that person, and finances may be such that they cannot hire a medical professional to come to the home.<sup>33</sup> The Medicare home care benefit is one vehicle that could help with this issue, but it is limited.<sup>34</sup> The financial burden for caregivers of the terminally ill is also substantial. One study found that 10–16% of terminal patients or their families had to take out a loan, deplete their savings accounts, or obtain an additional job to cover medical care costs.<sup>35</sup> Another study found that 31% of families of seriously ill patients spent all or most of their personal savings on health care for that patient.<sup>36</sup> It is also difficult for family members to maintain employment while caring for a terminal loved one. About 77% of caregivers for terminally ill cancer patients said that they missed work because of their caregiving responsibilities.<sup>37</sup> These familial burdens weigh on terminal patients. These patients can experience feelings of stress and helplessness because of the costs their family members experience.<sup>38</sup> Patients may also feel anxiety about the financial turmoil that these family members will incur after the patient has

---

<sup>31</sup> Noah, *supra* note 4, at 1.

<sup>32</sup> *Id.* at 14–15.

<sup>33</sup> Muriel R. Gillick, *How Medicare Shapes the Way We Die*, 8 J. HEALTH & BIOMEDICAL L. 27, 51 (2012).

<sup>34</sup> *Id.*

<sup>35</sup> E. J. Emanuel et al., *Understanding Economic and Other Burdens of Terminal Illness: The Experience of Patients and Their Caregivers*, 132 ANNALS INTERNAL MED. 451, 451 (2000).

<sup>36</sup> K. Covinsky et al., *The Impact of Serious Illness on Patients' Families: SUPPORT Investigators Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment*, 272 J. AM. MED. ASS'N 1839, 1839 (1994).

<sup>37</sup> Eva Grunfeld et al., *Family Caregiver Burden: Results of a Longitudinal Study of Breast Cancer Patients and Their Principal Caregivers*, 170 CAN. MED. ASS'N J. 1795, 1795 (2004).

<sup>38</sup> Greer Donley & Marion Danis, *Making the Case for Talking to Patients About the Costs of End-of-Life Care*, 39 J.L. MED. & ETHICS 183, 184 (2011).



## EXPANDING THE SCOPE OF BIOETHICS MEDIATION

died.<sup>39</sup> Terminal illness negatively impacts entire families, and those consequences weigh heavily on the patient.

### 2. Procedural Pressures on End-of-Life Patients

Second, procedural pressures burden patients. Government involvement with medicine adds its own pressures to the hospital care. Many decades of debate over health care reform have added buzzwords and political jargon to the conversation about end-of-life care. For instance, one debate about the Affordable Care Act was about the addition of “death panels.”<sup>40</sup> These largely mythical panels of bureaucrats would decide whether or not certain groups of Americans were “worthy” of end-of-life treatment.<sup>41</sup> Although these conversations were full of inaccuracies and political motivations, the conversation about end-of-life care, and particularly Medicare’s role in “promoting a good death,” is largely seen as off-limits.<sup>42</sup> This is unfortunate, because studies have shown that terminal patients have a better quality of life

---

<sup>39</sup> *Id.*

<sup>40</sup> Gillick, *supra* note 33, at 28.

<sup>41</sup> Although the rhetoric around “death panels” is based on a misperception of the proposed law, these misperceptions have persisted. The Affordable Care Act contained a provision that would have created a review board that would recommend ways to cut Medicare spending. Jason Millman, *It's Time to Bury the "Death Panel" Myth for Good. Is This the Way to Do It?*, WASH. POST (Sept. 17, 2014), <https://www.washingtonpost.com/news/wonk/wp/2014/09/17/its-time-to-bury-the-death-panel-myth-for-good-is-this-the-way-to-do-it/>. That provision has since been removed. *Id.* This board was targeted during the heated health care debate in 2009 and the “death panel” language was created. *Id.* During that debate, Sarah Palin, Governor of Alaska, spoke these infamous words: “The America I know and love is not one in which my parents or my baby with Down Syndrome will have to stand in front of Obama’s ‘death panel’ so his bureaucrats can decide, based on a subjective judgment of their ‘level of productivity in society,’ whether they are worthy of health care. Such a system is downright evil.” Harold Pollack, *Let's Talk About 'Death Panels': It's Time to Revisit a Good Idea that was Distorted by Demagoguery*, POLITICO (July 6, 2014), <http://www.politico.com/magazine/story/2014/07/death-panels-108553>. Because these opinions persist, national conversations about preparing for death and end-of-life care have been nearly impossible over the past five years. Millman, *supra* note 41. Brendan Nyhan, an assistant professor at Dartmouth, conducted research to understand why the death panel rhetoric persists, even though accurate information has been disseminated. His study reveals that, when readers are well-informed supporters of Sarah Palin and her point of view, corrective information can actually strengthen belief in death panels. Brendan Nyhan et al., *The Hazards of Correcting Myths About Health Care Reform*, 51 MED. CARE 127 (2013). It seems, therefore, that Medicare review panels and honest conversations about death and dying will not be entering the American national discourse for some time.

<sup>42</sup> Gillick, *supra* note 33, at 28.

when they are able to discuss their preferences openly.<sup>43</sup> This sort of conversing should be promoted for the benefit of patients.

Typically, internal hospital procedure forces a choice between technological treatment and palliative care.<sup>44</sup> Patients with terminal illnesses are then faced with an impossible choice. One option is to return to the comfort of home, which is the preference of many terminal patients. However, upon returning home, these patients can only receive hospice care.<sup>45</sup> Hospice care focuses on managing pain and increasing comfort but does not actively treat illness.<sup>46</sup> The patient will die at home under this option. The other option is to treat the illness, often with simple measures like blood transfusions, and hopefully prolong life.<sup>47</sup> However, this option means that the patient must remain in the hospital, which comes with its own health risks, as well as a poorer quality of life.<sup>48</sup> This stark dichotomy between active care in the hospital and certain death at home forces patients to make huge compromises with their last days. Additional at-home treatment options should be provided for terminal patients in order to promote patient autonomy and allow for increased quality of life.

### 3. Patients Struggle to Communicate with Health Care Payers

Finally, patients are burdened by the limitations of health care payers. For terminal patients, this payer is typically Medicare, but could also be Medicaid, private insurance, or some combination thereof. Medicare, because it publicly ensures Americans over the age of 65, has major implications for end-of-life care.<sup>49</sup> Medicare is also the largest insurer in the United States, so it influences

---

<sup>43</sup> *Id.*

<sup>44</sup> Alexi A. Wright & Ingrid T. Katz, *Letting Go of the Rope: Aggressive Treatment, Hospice Care, and Open Access*, 357 NEW ENG. J. MED. 324, 324–27 (2007). Because of the financial limitations of hospice centers, patients who choose hospice care often forego not only medical treatment, but truly effective palliative treatments as well. *Id.* at 324.

<sup>45</sup> Gillick, *supra* note 33, at 31.

<sup>46</sup> *Hospice Care*, NAT'L HOSPICE & PALLIATIVE CARE ORG., [www.nhpco.org/about/hospice-care](http://www.nhpco.org/about/hospice-care). Hospice “focuses on caring, not curing.” *Id.* Support is provided to the patient’s family as well. *Id.*

<sup>47</sup> Gillick, *supra* note 33, at 31.

<sup>48</sup> *Id.*

<sup>49</sup> Because Medicare subsidizes costs for patients, physicians, and hospitals, health care has become a major government enterprise. For instance, Medicare serves over fifty million elderly and disabled persons each year, CENTERS FOR MEDICARE & MEDICAID SERVICES, 2013 SMI TREND TABLE (2013), and in 2013, the Medicare program represented about 16% of the federal budget. THE HENRY J. KAISER FAMILY FOUNDATION, MEDICARE AND THE FEDERAL BUDGET: COMPARISON OF MEDICARE PROVISIONS IN RECENT FEDERAL

## EXPANDING THE SCOPE OF BIOETHICS MEDIATION

the policies of other insurance companies and dictates what hospitals and other health care institutions will offer.<sup>50</sup> For these reasons, whatever is covered under Medicare is often what will be offered to terminally ill patients, regardless of age or financial status, across the United States.<sup>51</sup> Because Medicare offers substantial reimbursements for “high tech” hospital care, “high touch” hospice care has been greatly marginalized.<sup>52</sup> In this way, Medicare has fostered an aggressive approach to end-of-life care to the detriment of patients.<sup>53</sup> Similarly, uninsured individuals lack adequate access to palliative care.<sup>54</sup> These patients are forced to rely on emergency room treatment and expensive hospital stays for symptoms that could easily be managed in the comfort of their homes.<sup>55</sup> Public insurance reform is needed in

---

DEBT AND DEFICIT REDUCTION PROPOSALS (2013). Because Medicare influences the majority of end-of-life care, and elder care generally, cases are often contested. Although the Centers for Medicare and Medicaid Services (CMS) has sought to be efficient and fair, that has been a difficult goal to achieve. The immense volume of Medicare cases that CMS faces requires cases to be processed in bulk. Phyllis E. Bernard, *Mediating with an 800-Pound Gorilla: Medicare and ADR*, 60 WASH. & LEE L. REV. 1417, 1425 (2003). Due process requires that each of the millions of patients, providers, and hospitals who receive Medicare funding also receive some sort of hearing whenever there is a Medicare dispute. *Id.* However, because formal hearings are slow, expensive, and can vary wildly in outcome, Medicare disputes are not handled individually, but in large batches. *Id.* It is particularly important that disputes be handled quickly because the results of Medicare disputes often impact the course of the patient’s treatment. It is also important that the outcomes of these hearings be consistent; CMS is prohibited from resolving disputes in an arbitrary and capricious manner. *Id.* These requirements have typically resulted in impersonal hearings.

However, the Administrative Conference of the United States (ACUS) has worked to address these issues. *Id.* at 1426. In 1986, ACUS found that the Medicare appeals system was a “patchwork with differing administrative and judicial review requirements” that needed to be revised. *Id.* (quoting ACUS No. 86-5, § 305.86-5 Medicare Appeals, 51 Fed. Reg. 46,987 (Dec. 30, 1986)). Several modifications were proposed, including replacing the Provider Reimbursement Review Board (PRRB) adjudications with ADR. *Id.* at 1426. In 1995, ACUS suggested that PRRB should use ADR instead of adjudication. *Id.* Those in the government and provider communities that used PRRB adjudication supported that recommendation and were willing to make the change. *Id.* at 1426–27. In 1998, CMS implemented a pilot in-house mediation program, which is considered a success by both health care providers and government representatives. *Id.* at 1427.

<sup>50</sup> Sean R. Tunis, *Why Medicare Has Not Established Criteria for Coverage Decisions*, 350 NEW ENG. J. MED. 2196, 2197 (2004).

<sup>51</sup> Gillick, *supra* note 33, at 29.

<sup>52</sup> *Id.* at 35.

<sup>53</sup> *Id.*

<sup>54</sup> Patricia A. Grady, *Caring for the Dying: The Importance of Nursing*, 2 J. HEALTH CARE L. & POL’Y 298, 307 (1999).

<sup>55</sup> *Id.*

order to adequately provide for the needs of terminal patients at the end of their lives.

## *B. Failures in Training and Communicating with the Health Care Industry*

### *1. Physician Training in End-of-life Issues*

In order to address these issues, it is important for medical professionals to establish a caring relationship with their patients in their last days. Ideally, the physician-patient relationship would be collaborative; it would be structured to “increase trust, create mutual respect and incorporate the diverse competencies of physician and patient.”<sup>56</sup> Unfortunately, physicians are often not equipped to address the social and financial burdens of their terminally ill patients. There are two reasons why physicians typically avoid the concerns of their terminal patients. First, research shows that caring for the terminally ill forces medical professionals to confront their own mortality.<sup>57</sup> Physicians may become afraid, and although it is unintentional, physicians will avoid their terminally ill patients as a result. Second, physicians are trained to conquer illness and beat disease. When patients reach end-of-life care, physicians are forced to recognize either their failure at “beating” death or the impossibility of that mission. Patients, therefore, are often avoided in their last days, instead of being met with care and concern by their physicians.

Because of this, “existential care” is typically left to nurses.<sup>58</sup> However, nurses are not frequently trained to handle the difficult and nuanced questions asked by terminal patients. It takes a “special level of sensitivity” for nurses and other health care personnel to understand questions and respond to their overwhelmed and distressed patients at end-of-life.<sup>59</sup> Even once these concerns are understood, it becomes the job of the nursing staff to “devise a procedure for providing empathetic support.”<sup>60</sup> This is an excessive burden to place on nursing staff, who are not trained in existential care. As a result, patient needs at end-of-life are frequently unmet.

Not only are medical professionals untrained in the full complexity of end-of-life issues, but they can exhibit vastly different values than their patients in

---

<sup>56</sup> Edward J. Bergman, *Managing Conflict in Clinical Health Care with Diminished Reliance on Third Party Intervention: Forging an Ethical and Legal Mandate for Effective Physician-Patient Communication*, 15 CARDOZO J. CONFLICT RESOL. 473, 476 (2014)

<sup>57</sup> Smith, *supra* note 15, at 476 (internal citations omitted).

<sup>58</sup> Rob Houtepen & David Hendrikx, *Nurses and the Virtues of Dealing with Existential Questions in Terminal Palliative Care*, 10 NURSING ETHICS 377, 377 (2003).

<sup>59</sup> Smith, *supra* note 15, at 476–77.

<sup>60</sup> *Id.*

## EXPANDING THE SCOPE OF BIOETHICS MEDIATION

regards to death and dying. As previously discussed, physicians are healers by training and strive to avoid death through their work. While physicians think of death as something to beat, patients may conceive of death quite differently. For instance, it may be more important to a patient that she live and die with dignity than to hold on to a few extra weeks of life through an invasive and painful procedure. Physicians may strongly disagree with this course of action, and the patient's family members may be distraught by the notion that their loved one is "choosing to die." Conflicts arise as a result, and typically, the patient is overpowered by the will of her physicians and family. These various and often competing values are only the tip of the iceberg in the complexity of end-of-life care, as well as the conflicts that often result.

### *2. Grounds for Conflict Between Patients, Physicians, and Families*

End-of-life care is notorious for conflicts among caregivers, patients, and their family members or surrogates. This should come as no surprise given "medicine's scientific, psychological and language complexities, high stakes, fragmentation of care, multiplicity of players, time constraints, institutional politics, cultural differences, competing philosophies and economic dimensions."<sup>61</sup> Most of these clinical conflicts arise from common instances of poor communication.<sup>62</sup> This can be information that was poorly communicated by one or more parties, cultural conflicts, or a clash of personalities.<sup>63</sup> However, there are some instances of clinical conflict that center on a difference in values or a legitimate moral question.<sup>64</sup> These conflicts typically arise in end-of-life situations.<sup>65</sup> In fact, one study found that

---

<sup>61</sup> Bergman, *supra* note 56, at 473.

<sup>62</sup> *Id.*; Carol B. Liebman, *Introduction to the Symposium Issue on Alternative Dispute Resolution Strategies in End-of-Life Decisions*, 23 OHIO ST. J. ON DISP. RESOL. 1, 8 (2007).

<sup>63</sup> The modern hospital system is ripe with this type of miscommunication and conflict. Not only do physicians work under extreme time pressure with too little sleep, but they must also explain complex information and deliver bad news to vulnerable patients and their families. Liebman, *supra* note 62, at 8. This leads to difficulties in communication. Additionally, any patient's care team is dispersed between different specialties and areas of the hospital. *Id.* The number of health care professionals involved in the case increases as the case gets more complicated. *Id.* This only adds to the probability of miscommunication. Finally, family members who come and go from the hospital each speak with a different member of the care team and typically only hear part of the relevant medical facts. *Id.* Conflict then erupts from these multiple sources of miscommunication, which is only made worse by the fact that many patients and families distrust hospitals and physicians. *Id.*

<sup>64</sup> Bergman, *supra* note 56, at 473–74.

<sup>65</sup> *Id.* at 474.

conflict occurred in 78% of cases in which patients, physicians, and families made decisions about limiting life-sustaining medical treatment.<sup>66</sup> Even though end-of-life cases have traditionally centered on a patient's right to "die with dignity,"<sup>67</sup> they now often include third parties who insist on life-sustaining medical treatment that the health care team finds "medically inappropriate."<sup>68</sup> Although these conflicts are common, many patients and surrogates find these challenges impossible to manage on their own.<sup>69</sup> When patients and their families need assistance in navigating a medical conflict, there are a couple of processes available to them.<sup>70</sup> The old standard in clinical conflict resolution is ethics consultation, but academics and hospitals alike have become interested in a new kid on the block: bioethics mediation.

#### IV. THE CURRENT ROLE OF BIOETHICS MEDIATORS

Since the 1970s, ethics consultation has been a staple of end-of-life care.<sup>71</sup> Ethics consultation is typically offered by a member or members of hospital ethics committees. Ethics committees are multidisciplinary groups comprised

---

<sup>66</sup> Catherine M. Breen et al., *Conflict Associated with Decisions to Limit Life-Sustaining Treatment in Intensive Care Units*, 16 J. GEN. INTERNAL MED. 283, 285 (2001).

<sup>67</sup> Thaddeus M. Pope & Ellen A. Waldman, *Mediation at the End of Life: Getting Beyond the Limits of the Talking Cure*, 23 OHIO ST. J. ON DISP. RESOL. 143, 146 (2007).

<sup>68</sup> *Id.*

<sup>69</sup> Bergman, *supra* note 56, at 473.

<sup>70</sup> *Id.*

<sup>71</sup> Charity Scott, *Ethics Consultations and Conflict Engagement in Health Care*, 15 CARDOZO J. CONFLICT RESOL. 363, 364 (2014). It all started with Karen Ann Quinlan in 1976. Quinlan was a young woman in a persistent vegetative state whose father asked physicians to remove the respirator that assisted her breathing. *Id.* He believed his daughter would not have wanted to be kept alive if she no longer had any brain function and could not live apart from machines. *Id.* Quinlan's father sought the advice of clergy and was convinced of the moral rightness of his request. *Id.* The physicians, however, would not withdraw the respirator because to do so conflicted with their professional judgment. *Id.* At trial, the court endorsed the concept of a hospital-based ethics committee to deal with similar future cases. *Id.* This committee could help address challenging decisions involving ethical issues and relieve some of the responsibility from the medical professionals working on the case. Since that ruling, the United States has had ethics committees who help in such cases. *Id.* at 364–65.

Because PVS and other incompetency cases were the foundation of ethics consultation, bioethics mediators have traditionally been used to assist with these issues. Therefore, in much of the bioethics and end-of-life literature, end-of-life disputes are presumed to include incompetence and decisionmaking by surrogacy. *See, e.g.,* Pope & Waldman, *supra* note 67, at 145 (noting the limitations on effective bioethics mediation in cases involving futility disputes).

## EXPANDING THE SCOPE OF BIOETHICS MEDIATION

of professionals from different backgrounds including medicine, nursing, law, pastoral care, and social work.<sup>72</sup> These committees were established to support and advise patients, families, and health care professionals as they confront conflicts in delicate health care circumstances.<sup>73</sup> Their role is to advise and facilitate conversation, typically between health care professionals and the families of terminal patients.<sup>74</sup> The Joint Commission<sup>75</sup> actually requires its accredited hospitals to have a process that allows staff, patients, and families to address ethical issues or “issues prone to conflict.”<sup>76</sup> For several decades, all ethical questions or other “value-laden conflicts” over patient care were addressed using an ethics committee or a team of consultants.<sup>77</sup>

However, scholars have more recently advocated for a different method of settling clinical conflicts: bioethics mediation. Nancy N. Dubler and Carol B. Liebman coined the phrase “bioethics mediation” in their book, *Bioethics Mediation: A Guide to Shaping Shared Solutions*, which was originally published in 2004.<sup>78</sup> According to Dubler and Liebman, bioethics mediation “combines the clinical substance and perspective of bioethics consultation with the tools of the mediation process, using the techniques of mediation and dispute resolution . . . .”<sup>79</sup> As with mediation in other contexts, bioethics mediators act as neutral third parties who assist interested individuals in

---

<sup>72</sup> Thaddeus Mason Pope, *The Growing Power of Healthcare Ethics Committees Heightens Due Process Concerns*, 15 CARDOZO J. CONFLICT RESOL. 425, 425 (2014).

<sup>73</sup> *Id.*

<sup>74</sup> *Id.*

<sup>75</sup> The Joint Commission is an accrediting organization that certifies almost 21,000 health care organizations and programs in the United States. *About the Joint Commission*, JOINT COMMISSION, [http://www.jointcommission.org/about\\_us/about\\_the\\_joint\\_commission\\_main.aspx](http://www.jointcommission.org/about_us/about_the_joint_commission_main.aspx) (last visited Apr. 4, 2016). Accreditation by the Joint Commission is recognized as “a symbol of quality that reflects an organization’s commitment to meeting certain performance standards.” *Id.*

<sup>76</sup> Scott, *supra* note 71, at 365 (internal citation omitted).

<sup>77</sup> *Id.* at 363–64.

<sup>78</sup> NANCY N. DUBLER & CAROL B. LIEBMAN, *BIOETHICS MEDIATION: A GUIDE TO SHAPING SHARED SOLUTIONS* (2d ed. 2011).

<sup>79</sup> Nancy N. Dubler & Carol B. Liebman, *Bioethics: Mediating Conflict in the Hospital Environment*, 59 DISP. RESOL. J. 32, 35 (2004). Bioethics mediation process is represented by the acronym STADA, which is described in Part V. Additionally, the goals of bioethics mediation are to “identify the parties to the conflict . . . ; level the playing field to minimize disparities of power, knowledge, skill, and experience . . . that separate the medical professional, patient, and family; help the parties define their interests; help maximize options for a resolution of the conflict; search for common ground or areas of consensus; [and] ensure that the consensus can be justified as a principled resolution, compatible with the principles of bioethics and the legal rights of patients and families . . . .” DUBLER & LIEBMAN, *supra* note 78, at 12.

communicating their points of view.<sup>80</sup> Bioethics mediators also help the parties actively listen to one another and facilitate conversation as the parties come to a conclusion that is agreeable to everyone involved. In a clinical setting, these parties will usually be (1) members of the medical team who disagree among themselves over the best course of action or (2) medical staff and the family of the patient who disagree over a treatment plan or best outcome. The bioethics mediator seeks to “clarify misperceptions, diffuse emotions, surface common interests, and encourage creative brainstorming.”<sup>81</sup>

Unlike ethics consultants, bioethics mediators are trained in clarifying information and diffusing emotion, two skills that are essential to the high-stress, values-laden decisions that must be made at end-of-life.<sup>82</sup> However, bioethics mediation is not just like mediation in any other context. One large difference is the roles of social norms.<sup>83</sup> In most mediation contexts, parties are invited to create the rules and standards that guide the resolution.<sup>84</sup> Rarely do existing social or legal norms impose a conclusion on the process; unless an individual mediator chooses to include them, these types of external values are considered largely irrelevant to the process.<sup>85</sup> In contrast, bioethics mediation requires the mediator to identify the legal and ethical norms that apply to the conflict and asks that the parties focus on those concerns in reaching their agreement.<sup>86</sup> For instance, health care professionals and the family members of a terminally ill patient may have separate ideas about a course of action, but neither party has considered what the patient would want if she were able to make the decision. In these instances, the bioethics mediator must remind the parties that the patient’s autonomy must be respected and their choices should be approximated. Bioethical values will shape the nature of the mediation.

### A. *The Benefits of Bioethics Mediation*

Some scholars have been critical of the traditional ethics consultation model in favor of bioethics mediation. These commentators are concerned with a range of issues that the ethics consultation model presents, including

---

<sup>80</sup> Ellen Waldman, *Bioethics Mediation at the End of Life: Opportunities and Limitations*, 15 CARDOZO J. CONFLICT RESOL. 449, 452 (2014).

<sup>81</sup> *Id.*

<sup>82</sup> *Id.* at 463–65.

<sup>83</sup> Ellen A. Waldman, *Identifying the Role of Social Norms in Mediation: A Multiple Model Approach*, 48 HASTINGS L.J. 703, 707 (1997).

<sup>84</sup> *Id.* at 708.

<sup>85</sup> Waldman, *supra* note 80, at 456.

<sup>86</sup> *Id.*



## EXPANDING THE SCOPE OF BIOETHICS MEDIATION

limited contact with patients and their families, the prevalence of caregiver referrals, and decisionmaking by individuals who are in no way experts in discerning moral claims.<sup>87</sup> These issues stem from a power imbalance between the patient and the ethics consultant, who too frequently represents the physician and the hospital itself. In this structure, the patient's role is secondary to that of the ethics consultant, despite the belief that autonomy is key to ethical patient care.<sup>88</sup> Another problem frequently cited is a lack of unifying training requirements for ethics consultants, as well as the absence of uniform standards for decisionmaking.<sup>89</sup> Bioethics mediation aims to address these issues and truly elevate patient autonomy in regards to the end-of-life process.

Bioethics mediation hopes to fill the gaps in the ethics consultation model, holding itself out to be "an inclusive, non-hierarchical, non-coercive process," in which parties have conflicting views, but work to come to consensus because "a decision is, nonetheless, required."<sup>90</sup> This approach has gained momentum in bioethics literature because of its "humanistic, cathartic and egalitarian features," even though there are still some significant obstacles to implementing bioethics mediation on a wide scale.<sup>91</sup> In the few places where bioethics mediation has been implemented, the infusion of mediation skills into the clinical ethics process has been greatly appreciated.<sup>92</sup> Clinical ethics will continue to move in the direction of bioethics mediation. The American College of Healthcare Executives states that health care executives should "[w]ork to ensure that there is a process in place to facilitate the resolution of conflicts that may arise when values of patients and their families differ from those of employees and physicians."<sup>93</sup> This sort of broad role requires ethics committees and ethics consultants to be skilled, not only in ethics, but "also in communication, interpersonal relationships, and conflict management."<sup>94</sup> If ethics consultation is to appropriately address the conflicts that arise during end-of-life care, bioethics mediation must continue to be implemented around the country.

---

<sup>87</sup> Bergman, *supra* note 56, at 474.

<sup>88</sup> *Id.*

<sup>89</sup> *Id.*

<sup>90</sup> *Id.* at 474–75.

<sup>91</sup> *Id.* These issues of implementation will be discussed below.

<sup>92</sup> The preeminent Clinical Ethics Mediation Program exists at the University of Pennsylvania.

<sup>93</sup> ACHE Code of Ethics § II(D) (AM. COLL. OF HEALTHCARE EXECUTIVES 2011), [http://www.ache.org/abt\\_ache/code.cfm#patients](http://www.ache.org/abt_ache/code.cfm#patients).

<sup>94</sup> Scott, *supra* note 71, at 366.

*B. The Limited Scope of Bioethics Mediation*

Although bioethics mediation offers much-needed skills to the field of ethics consultation, this upcoming field has been largely limited in scope. In the overwhelming majority of cases, bioethics mediators are used in cases where the patient is incompetent, or unconscious, and unable to make her own medical decisions. In these cases, her family is making medical decisions on her behalf, and the dispute occurs because the family disagrees with the medical team's course of action.<sup>95</sup> These are often medical futility disputes, in which medical treatment will not help the condition of the patient, and the family members have two options. Either they can come to full understanding of the futility and cease treatment, or they can insist on additional care.<sup>96</sup> This limitation means that some of bioethics mediation's best qualities are nearly inapplicable. The bioethics mediator need not "excavate underlying needs and interests, identify common ground, and push disputants toward more moderate, creative, and mutually satisfying outcomes" in medical futility disputes.<sup>97</sup> In these cases, there is no middle ground.<sup>98</sup> Either the provider will convince the family that care is futile, or the family will impose its wishes to continue treatment, regardless of the outcome. In almost all cases, the health care professional concedes to the family's wishes, and treatment continues.<sup>99</sup> The two parties are not required to listen openly to one another and come to a conclusion based on bioethics principles. Bioethics mediation has been limited to the point of inefficacy.<sup>100</sup> Bioethics mediation should be utilized in cases where competent patients, plagued by the challenges discussed in Part III, are attempting to exercise autonomy and direct their own end-of-life care.<sup>101</sup>

---

<sup>95</sup> In fact, the foundational text on bioethics mediation, written by Nancy Dubler and Carol Liebman, uses examples and application of principles that are confined to this very narrow context. DUBLER & LIEBMAN, *supra* note 78, at 3–8.

<sup>96</sup> Pope & Waldman, *supra* note 67, at 145.

<sup>97</sup> *Id.* at 143.

<sup>98</sup> *Id.*

<sup>99</sup> *Id.*

<sup>100</sup> *Id.* Pope & Waldman believe there are limits to the efficacy of bioethics mediation as originally conceived. *See id.*

<sup>101</sup> Waldman, *supra* note 80, at 456–57. Walden, in her article *Bioethics Mediation at the End of Life: Opportunities and Limitations*, does include a bioethics mediation example that includes a competent patient. In the scenario she creates, a patient is suffering from gangrene, and a bioethics mediation is called for the patient, family, and hospital staff. The family and care team strongly believe that the patient should amputate the affected limb. They would all prefer life for the patient over the loss of the limb. However, the patient adamantly refuses amputation. He says he would "rather die than lose the limb." *Id.* at 456. Even though one family member joins the patient's side, she is pressured by the other

## EXPANDING THE SCOPE OF BIOETHICS MEDIATION

### V. BIOETHICS MEDIATION FOR COMPETENT PATIENTS AT END-OF-LIFE

The application of bioethics mediation need not be so narrow. As seen in Part III, competent end-of-life patients struggle to exercise autonomy and direct their own care. Unlike cases of medical futility, there is middle ground in disputes between competent patients and their health care providers, payers, and families. In these contexts, bioethics mediators can clarify medical facts, explore treatment options, and help develop solutions that reflect the patient's values and uphold bioethical principles.<sup>102</sup> Expanding the scope bioethics mediation would not only fulfill the purpose of bioethics mediation in the first instance, but would also solve many of the problems competent patients face at end-of-life.

#### A. Advocate for Patient Autonomy at End-of-Life

By mediating disputes between competent patients and other interested parties, bioethics mediators can serve as patient advocates, advancing patient autonomy in a system built for physician beneficence. Autonomy is the preeminent value in modern American culture and is the bioethical principle of greatest concern at end-of-life. Autonomy is also valuable at end-of-life

---

interested parties and decides to back down. In this fictional, yet realistic scenario, Waldman emphasizes the role of the bioethics mediator; she is to give deference to the wishes of the patient. *Id.* at 457. According to Waldman, "[l]egal and ethical precepts state that the patient's autonomy and decisional authority trumps the preferences of either clinical staff or family." *Id.*

Even within the context of incompetent patients, there are some instances where bioethics mediation will not resolve conflict or miscommunication. Liebman mentions several instances. First, the patient may not have the mental capacity to make an autonomous choice. Liebman, *supra* note 62, at 15. This issue exists in classical mediation as well. Second, the patient or family may lack the "emotional strength" to make decisions about life and death. *Id.* For this reason, the care team may need to take on more responsibility. Third, the family situation may be difficult or strained. If the family is dysfunctional, it may be impossible for them to work together or come to some sort of agreement about care. *Id.* Liebman also mentions the Terri Schiavo case, in which political activists and lobbying groups brought their own agendas to the case. *Id.* This serves to escalate the family conflict for the purpose of publicity. Liebman notes, however, that bioethics mediation may still serve a helpful purpose in these cases. *Id.* at 15–16. Although an agreement is not reached, meeting with a bioethics mediator can help the parties understand each other's perspectives and can provide some previously unheard health care facts, like treatment options, and can give each interested party increased clarity as to his or her own goals and values. *Id.* at 16.

<sup>102</sup> DUBLER & LIEBMAN, *supra* note 78, at 7.

because, as patients face severe physical and emotional pain, their personal quality of life questions are exceptionally important.<sup>103</sup> It is crucial that patients are able to express their preferences for where they will live their final days. Although medical custom favors beneficence, bioethics mediators can elevate patients in the course of mediation, helping them to express their autonomous desires at end-of-life.

However, pure autonomy is difficult to achieve. Not only is hospital care complex and challenging to navigate, but the beneficence model of care, which emphasizes the physician's opinion of what is best for the patient, has also left lingering expectations in the minds of patients.<sup>104</sup> The complexity of the physician's job and their desire to avoid conversations about death can lead to a lack of information for patients to make informed decisions.<sup>105</sup> Even if they have enough information to form an opinion, patients may not want to speak out in the face of competing opinions by their doctors and family members.<sup>106</sup> The bioethics mediator, as a neutral third party, can mediate these disputes in a way that promotes the patient's autonomy.<sup>107</sup>

### *1. The STADA Process*

The first tool that bioethics mediators have at their disposal is the STADA method. STADA is an acronym that serves as an outline for the steps in a mediation.<sup>108</sup> Dubler and Liebman, in their foundational book on bioethics mediation, describe the process this way:

S—Sit down: Sitting with the patient and family is a comforting gesture. In the hospital, most of the staff are in the patient's room for very short amounts of time. Families appreciate genuine focus and attention from the bioethics mediator.

---

<sup>103</sup> Smith, *supra* note 15, at 477.

<sup>104</sup> Garwin, *supra* note 8, at 100.

<sup>105</sup> *Id.*; Smith, *supra* note 15, at 476 (internal citations omitted).

<sup>106</sup> See Noah, *supra* note 4.

<sup>107</sup> Bioethics mediators attempt to maintain neutral, just as in classical mediation. However, bioethics mediators are often employed by the hospitals in which they work, and therefore, their neutrality is at risk. See DUBLER & LIEBMAN, *supra* note 78, at 21–24. Their position as hospital employees may affect their ability to advocate for the autonomy of the patient if the patient is at odds with the physician, care team, or, even worse, their health care payer. More investigation is required in order to determine the full extent of the risk, and best practices may dictate that bioethics mediators be compensated through some other means. See *id.*

<sup>108</sup> *Id.* at 74.

## EXPANDING THE SCOPE OF BIOETHICS MEDIATION

T—Tell me about Mama: This is an opportunity for the family to talk about their ill family member. Importantly, asking the family about the patient empowers them as experts in an essential part of treatment.

A—Admire: Mediators practice stroking, which affirms what the family has stated about the patient, and commends them for their concern for her. This enhances the family's sense that they are appreciated as part of the process.

D—Discuss: Discussion allows the medical staff to present the facts of the case, including diagnosis, prognosis, and treatment alternatives. In some cases, this will be the first time that a family will be told that their loved one is dying.

A—Ask: Finally, the family is asked what the patient would want if she could speak. In making this decision, the family is asked to consider the patient's lifestyle, values, and preferences.<sup>109</sup>

This is the foundational process for mediation and is used often in the limited context of bioethics mediation today: incompetent patients whose end-of-life decisions are being made for them by family members. This process can and should be expanded and used with competent patients. By adjusting each step to include the patient, the integrity of the process is retained, but the patient is able to be a part of the conversation. This process is outlined below:

S—Sit down: Sitting with the patient and her family will be comforting, not only to the family, but to the patient as well. The bioethics mediator will provide the patient with genuine focus and attention.

T—Tell me about yourself: Instead of the family members talking about the patient, this is an opportunity for the patient to discuss her own lifestyle, values, and preferences. The patient will be elevated to the level of expert on these issues.

A—Admire: Stroking, in this instance, is used to affirm the patient for any number of reasons, based on what she has shared with the mediator. For example, the mediator can praise the patient for persevering over personal struggle or for showing concern for her family.

---

<sup>109</sup> *Id.* at 74–75.

D—Discuss: The medical staff will still present the diagnosis, prognosis, and treatment alternatives. It is important for the patient, as well as her family members, to be fully apprised of the medical realities.

A—Ask: Finally, the patient is asked how she would like to proceed. The family and medical staff may also share their opinions, but the patient is encouraged to base this decision on her lifestyle, values, and preferences.<sup>110</sup>

The STADA process is particularly useful if the patient has not expressed a treatment preference. Asking the patient about their values generally, and then discussing in detail the facts of their case, may lead them to state preferences they had not vocalized before. This is particularly true if the patient has strong-willed family members,<sup>111</sup> a domineering physician,<sup>112</sup> or has not been given complete information about her prognosis.<sup>113</sup> The STADA process can be used to fully inform the patient and empower her to establish and express treatment preferences.

## 2. Conflict Mediation

However, if the patient is opinionated about her treatment plan, a different process may be more effective. Conflict can arise between two or more interested parties as an effect of social and procedural pressures. For example, the family might believe that the patient should “fight” the disease and “do everything possible” to become well again.<sup>114</sup> The physician, in her capacity as healer, may agree with the family and continue to push for invasive treatment. If surgery has a better chance of extending life, even for a year or two, the physician may prefer surgery. Additionally, many hospitals draw a harsh distinction between palliative care and active treatment.<sup>115</sup> If the patient is receiving even simple treatment measures, palliative care is not an option.<sup>116</sup> In the midst of these pressures, the patient may prefer to keep receiving blood

---

<sup>110</sup> The STADA method, as applied to competent end-of-life patients, is a theory created by the author. It follows directly from the STADA method described by Dubler & Liebman. *Id.* at 75.

<sup>111</sup> Noah, *supra* note 4, at 1.

<sup>112</sup> Smith, *supra* note 15, at 476 (internal citations omitted).

<sup>113</sup> *Id.*

<sup>114</sup> Noah, *supra* note 4, at 1.

<sup>115</sup> Gillick, *supra* note 33, at 31.

<sup>116</sup> *Id.*

## EXPANDING THE SCOPE OF BIOETHICS MEDIATION

transfusions, begin pain management therapy, and return home to live their final months. These situations are exceedingly common and can lead to outright conflict between patients, family members, physicians, and hospital administration.

In conflict cases, the bioethics mediator has a somewhat different task. Instead of advancing the patient's autonomy by helping them express an opinion, the mediator must help the parties find common ground while respecting bioethical principles. The first of these principles is autonomy, but in these cases, beneficence, non-maleficence, and justice may also be applied. Dubler and Liebman identify several goals for bioethics mediators as they work to settle bioethics conflicts between physicians and families.<sup>117</sup> These goals should also be applied in cases of conflict between the patient and other interested parties.

The first several goals center on elevating the status of the patient to that of the other interested parties. This process begins by identifying the parties to the conflict.<sup>118</sup> When the patient expresses discontentment, it may be difficult to tell from where the pressure originates. Understanding which parties are in conflict is essential to resolving the tension. Once the parties are discerned, the bioethics mediator must attempt to create a "level playing field," minimizing the disparities of power, knowledge, skill and experience that separate the parties.<sup>119</sup> These power disparities exist as a byproduct of the hospital as an institution.

The physician's role, access to information, and control of resources increase her power.<sup>120</sup> Patients, on the other hand, are bound by the "total institutional nature" of the hospital.<sup>121</sup> Their clothes have been taken, their lives have been scheduled, and they cannot leave without permission.<sup>122</sup> These institutional realities disempower the patient. Although these power imbalances cannot be completely cured through mediation, bioethics mediators can "ensure that power disparities do not deprive patients and families of their voices or their autonomy."<sup>123</sup>

This power imbalance will be different in each case. In some instances, the physician will have much more knowledge and experience than the patient or the family. In others, the family may be on more equal power terms with the physician, and the patient feels marginalized by both parties. In yet other

---

<sup>117</sup> DUBLER & LIEBMAN, *supra* note 78, at 12–13.

<sup>118</sup> *Id.* at 12.

<sup>119</sup> *Id.*

<sup>120</sup> *Id.* at 81–82.

<sup>121</sup> *Id.*

<sup>122</sup> *Id.*

<sup>123</sup> *Id.*

cases, the patient and physician may agree on the treatment plan, but the family members disagree and feel that their voices are not heard.<sup>124</sup> In each situation, the bioethics mediator can diffuse conflict and promote the patient's autonomous wishes for her treatment.<sup>125</sup> In fact, it is in the context of power imbalance that bioethics mediators act as advocates for the patient. Mediators do not often play the role of advocates. They are neutral parties that assist in finding common ground in the midst of a dispute. However, large power imbalances require the mediator to raise the disenfranchised party to the level of the powerful party or, at least, empower the patient enough so that her autonomy can be asserted.

### B. Address Cultural Concerns

Although autonomy is highly esteemed in the United States, not all cultures value autonomy as strongly. Modern bioethics is based on Western moral philosophy and Western biomedical perspectives,<sup>126</sup> but not every patient has Western values. When other cultural understandings of health, family, and decisionmaking come to bear on a case, conflict often occurs. Bioethics mediators are essential to resolving this conflict.

The most important values and preferences in any end-of-life decisionmaking process are those of the patient. This creates an essential difference as the bioethics mediator applies the STADA process to a culturally diverse case. In these instances, the bioethics mediator should not approach the STADA conversation with preconceived notions of which bioethical principles will apply. The goal of these conversations is to listen carefully to

---

<sup>124</sup> This may be particularly common in culturally diverse families. For instance, first generation immigrants may maintain the cultural values of their country of origin. However, second generation immigrants may be more acculturated to the values of the United States and therefore, may not feel beholden to the values of their country of origin, even though these values are still held by other members of their family.

<sup>125</sup> One scholar has commented on the lack of academic emphasis on the trust between the patient and physician. He believes that this oversight deemphasizes "the value of preserving patients' trust in their treating physicians at the end of life and therefore overlooks a powerful argument in support of [end-of-life] mediation." Robert Gatter, *Unnecessary Adversaries at the End of Life: Mediating End-of-Life Treatment Disputes to Prevent Erosion of Physician-Patient Relationships*, 79 B.U. L. REV. 1091, 1096 (1999). However, Gatter also argues that, "[A] policy of preserving or promoting medical trust is unwarranted and potentially destructive." Robert Gatter, *Faith, Confidence, and Health Care: Fostering Trust in Medicine Through Law*, 39 WAKE FOREST L. REV. 395, 396. Although positive public perception of medical professionals may be necessary to the success of any health care delivery system, he says that emotionally-based trust may be unnecessary. Instead, consumer confidence may be sufficient. *Id.* at 397.

<sup>126</sup> Kerry Bowman, *What Are the Limits of Bioethics in A Culturally Pluralistic Society?*, 32 J.L. MED. & ETHICS 664 (2004).



## EXPANDING THE SCOPE OF BIOETHICS MEDIATION

the patient and the family and to help the medical team direct the patient's care according to their culturally-held values.

In some instances, the patient and the family will not hold the same values. For instance, second generation immigrants may be more acculturated to the values of the United States than their parents. Therefore, these patients may not feel beholden to the values of their country of origin, even though these values are still held by other members of their family. This nuance complicates the conversation, and health care professionals may struggle to keep families engaged in these cases. However, bioethics mediators, through the STADA process, can help the family feel valued, unearth the different values and preferences of the interested parties, and find common ground. Bioethics mediation is an essential part of cultural competence in end-of-life care.

### *C. Educate Patients and Practitioners*

Bioethics mediators are also well-suited for patient and practitioner education. Patients and physicians do not always communicate well. Power imbalances, institutional procedure, and cultural differences exacerbate this problem. This means that patients and physicians have different and incomplete information as they attempt to form a treatment plan. Although difficulty in communication does not always rise to the level of conflict, conflict can be avoided by preventive and educational uses for bioethics mediation.

Patients would benefit from education on their end-of-life planning options. These options will likely include various treatment options, ranging from mild to aggressive. Palliate care is an option for many patients, particularly if treatment is no longer consistent with the patient's values and preferences, and various legal precautions are taken in case the patient becomes incompetent.<sup>127</sup> Presenting patients with full information for planning their end-of-life stages is a best practice and, in some instances, a legal requirement. For instance, nursing homes are required to educate their

---

<sup>127</sup> One such legal protection is advance directives. Advance directives are common documents used to preserve patient autonomy in case of incompetence. When a patient is no longer able to direct his or her own end-of-life care, advance directives contain the patient's preferences and ensure that they are followed. Ruth F. Maron, *Who Has A Will to Live?: Why State Requirements for Advance Directives Should Be Uniform*(Ly Revised), 24 REGENT U. L. REV. 169, 169 (2012). However, advance directives have drawbacks. First, the majority of Americans do not have advance directives, severely limiting their utility. *Id.* Second, even if an advance directive is in place, it may not be followed, either because the proxy pushes for additional treatment or because the physician finds that treatment futile. *See id.* at 188.

residents about their end-of-life care planning options and must also assist them in implementing an advance directive if they choose.<sup>128</sup> Additionally, health care professionals may benefit from education on bioethical issues. There are often great disparities between the preferences of patients and what physicians *think* patients prefer.<sup>129</sup> In fact, a study from the Robert Wood Johnson Foundation found that almost half of the tested physicians did not know that their patient's preferences were not to be resuscitated.<sup>130</sup> Physicians need mediation in order to better understand the needs and wants of their patients.

Bioethics mediators can resolve these problems by working with patients and physicians in caucus. Caucus meetings are a tool used by mediators in which private meetings are held with one party and the mediator.<sup>131</sup> Caucus meetings are an excellent opportunity to clarify issues in the conflict, “reality test” with one party, and examine power imbalances between the parties without the other party being able to weigh in.<sup>132</sup> Educational caucuses can easily be utilized as a preventive measure in order to avoid conflict between patients and other parties.

#### *D. Promote Increased Access to Palliative Care*

Finally, a key issue facing patients at end-of-life is lack of access to palliative care. Palliative care is scarce because it is often placed in opposition with active treatment.<sup>133</sup> Even minor active treatment precludes palliative care, placing patients in a serious dilemma as they plan their end-of-life process.<sup>134</sup> However, this stark contrast need not exist. One scholar defines palliative care as “specialized healthcare for anyone who is diagnosed with a serious and life-threatening illness, starting when they get the diagnosis, regardless of the prognosis.”<sup>135</sup> If hospitals were to adopt a similarly inclusive palliative care

---

<sup>128</sup> Julene Brown, *SNFs: Have You Reviewed Your Advance Directive Policy? Directives Should Be Reviewed Regularly to Ensure They Are Consistent with Resident Wishes*, 15 J. HEALTH CARE COMPLIANCE 51 (2013). This leads to further educational needs. For instance, the nursing home staff must be educated about advance directives and how to follow them. *Id.*

<sup>129</sup> Grady, *supra* note 54, at 306.

<sup>130</sup> *Id.*

<sup>131</sup> DUBLER & LIEBMAN, *supra* note 78, at 88.

<sup>132</sup> *Id.*

<sup>133</sup> Gillick, *supra* note 33, at 31.

<sup>134</sup> *Id.*

<sup>135</sup> R. SEAN MORRISON, POLICY BRIEF. NO. 43/2010, PALLIATIVE CARE: A NOVEL SOLUTION TO THE HEALTHCARE CRISIS 1 (Syracuse Univ. Maxwell Sch. of Citizenship & Pub. Affairs, Ctr. for Pol’y Res. 2010).

## EXPANDING THE SCOPE OF BIOETHICS MEDIATION

definition that embraces pain and comfort management as part of active treatment, this care might become available to many patients who desire it.

Additionally, palliative care is financially beneficial for both patients and the hospital.<sup>136</sup> Pain management costs much less than active treatment, both to administer and to receive.<sup>137</sup> For this reason, many hospitals are moving away from reserving palliative care until hospice and are incorporating pain management throughout the course of treatment for life-threatening illnesses.<sup>138</sup> However, hospice centers are concerned about their bottom lines as well. It has become common practice to hand-select patients for hospice that will bring the most money into the center.<sup>139</sup> Because hospice centers are denying care to certain patients for financial reasons, it is imperative that someone mediate disputes between patients and these centers. Bioethics mediation between the patient, the hospital, and the health care payer are essential to quality of life in a palliative care setting.

Unfortunately, bioethics mediators may have a more limited role in these instances. Bioethics mediators are trained to understand the desires of the patient and to find common ground between parties in conflict. However, mediators are not in a position to advocate for more treatment than the insurance company will cover. Depending on the leniency and willingness of the payer, there may be a place for bioethics mediators to arrange additional care in special circumstances. Additionally, bioethics mediators can discuss options openly and honestly so that patients truly know what care is available to them. However, patient advocacy for additional palliative care is an area of need that perhaps bioethics mediators are not best suited to fill.

## VI. CONCLUSION

Bioethics mediation is a fledgling field that shows great promise for mediating disputes between families and physicians as they care for terminal patients. It has done well in its early stages. However, the role of bioethics mediation should be expanded. End-of-life patients are plagued with many challenges, not just in health, but also in defining the content and meaning of their last years. The cost of medical care, cultural differences, and family preferences compound and often keep patients from exerting their autonomous choices. Bioethics mediators are ideally suited to mediate these disputes, thereby advancing bioethical principles and achieving the desires of each

---

<sup>136</sup> Katherine B. Ledden, *A Nudge in the Right Direction with a Stick the Size of CMS: Physician-Patient Communication at the End of Life*, 6 ST. LOUIS U.J. HEALTH L. & POL'Y 389, 396 (2013).

<sup>137</sup> *Id.* at 393–94.

<sup>138</sup> *Id.* at 397.

<sup>139</sup> *Id.* at 399–400.

patient at end-of-life. As bioethics mediation becomes a popular alternative to traditional clinical ethics and continues to expand across the country, its implementation should be as broad as the difficulties and disputes faced by end-of-life patients.